



U.S. Senator Judd Gregg, Chairman

Senate Committee on Health, Education, Labor and Pensions

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SENATE PASSES MEASURE PROTECTING AGAINST GENETIC DISCRIMINATION

Successful Bipartisan Bill Marks End of Gridlock

Washington, DC - Today the U.S. Senate passed a measure cosponsored by Senator Judd Gregg (R-NH), Chairman of the Senate Committee on Health, Education, Labor and Pensions, that aims to safeguard the privacy of genetic information as well as protect Americans from discrimination in health insurance and employment on the basis of their genetic information. This accomplishment comes after six years of gridlock on this important issue.

"We live in a world where the secrets of human life have been plotted out and sheep have been cloned. It only makes sense that the first civil rights legislation under my tenure as Chairman deals with the truly 21st century issue of genetic discrimination. This bill establishes in federal law, basic legal protections to enable and encourage individuals to take advantage of genetic screening, counseling, testing and new therapies," said Gregg.

"This bill protects the privacy of genetic information. And it protects individuals from discrimination in health insurance or employment based on their genetic information. Just as a man shouldn't be discriminated against because of the color of his skin, so too a healthy woman shouldn't suffer discrimination because of a genetic disease with which her mother was diagnosed," said Gregg.

"For six years both sides on this issue were stuck. I am pleased that this year we were able to break the impasse and get a bipartisan deal done. Today we are bringing public policy up to date with science and its recent breakthroughs. We do this to ensure that every American can benefit from our scientific progress without the worry of genetic discrimination," said Gregg.

S. 1053, The Genetics Non-Discrimination Act now moves to the House of Representatives for consideration.

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S. 1053 Genetics Non-Discrimination Act Summary:

Protects against genetic discrimination from health plans and insurance companies.

- Prohibits health insurance plans from denying an individual enrollment in the plan because of individual's or family member's genetic information.
- Prohibits health insurance plans from charging higher premiums to individuals because of individual's or family member's genetic information.
- Prohibits health insurance companies from basing premiums of a group health plan on genetic information of members (including family members) of the plan.

Keeps genetic information private:

- HHS privacy rules govern the use and disclosure of genetic information, except this bill also:
- Bans the use and disclosure of genetic information for insurance underwriting purposes.
- Bans the collection (i.e., requesting, requiring, and purchasing) of genetic information for purposes of underwriting.
- Prohibits insurance companies from collecting genetic information prior to enrollment in any plan.

Structure and Enforcement of Health Provisions:

- Creates a single federal standard for protection of genetic information, which does not exist today.
- Generally builds on the existing law framework under HIPAA. In doing so, this ensures that genetic information is treated consistently with other health information and individuals, who face discrimination, whether they are healthy, sick or disabled, have the same rights and remedies.
- The non-discrimination provisions are enforced in same manner as current law, however some procedural protections are established for group health plan participants including the ability to seek injunctive relief and to have retroactive reinstatement of coverage for violations. Penalties may be payable to the individual or levied against the plan.
- The privacy provisions are enforced in the same manner as HIPAA privacy rules through HHS Office of Civil Rights; with the same civil penalty and criminal enforcement structure.

Protects employees from genetic discrimination at the workplace:

- Prohibits the use of genetic information in employment decisions, such as hiring, firing, job assignments, and promotions.
- Prevents the acquisition and disclosure of genetic information.
- Applies the same procedures and remedies as other forms of employment discrimination, such as race under the Civil Rights Act of 1964 and disabilities under the Americans with Disabilities Act of 1990.

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